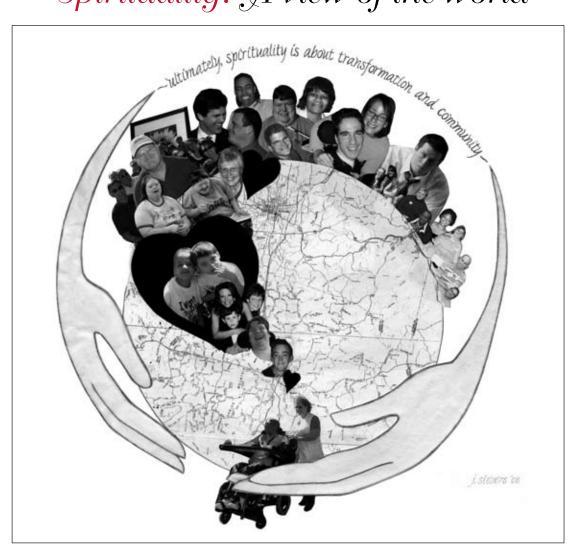
## BREAKING GROUND

## Spirituality: A view of the world





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Cover collage by Joyce Elaine Sievers

#### **CONTACT INFORMATION**



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## Spirituality: A view of the world

#### BY JOYCE ELAINE SIEVERS

So, how does one describe "spirituality"? Its meaning

can take a variety of forms. Such a word may explain your view of the world; the view from which your actions emanate. The Oxford dictionary defines spirituality as "of, relating to, or affecting the human spirit or soul as opposed to material or physical things." Thus, spirituality is not concerned with money or "things", but your place in this world, such as acceptance, belonging, relationships, self-image, freedom, opportunities to contribute, hope, joy, beauty and one's gifts.

For me, spirituality is viewing our world as sacred ground and seeing each person that I meet as a soul making a journey through this sacred ground. With this view, my personal question then becomes, how do I support these souls in experiencing these aspects of spirituality on his/her journey through this sacred ground? How do we grace one another's lives, infusing the most ordinary things with the luster of our unique beauty and gifts? The following are some experiences related to my view of spirituality.

I think of Mike and his opportunity to contribute as one of the individuals participating in the art program that I directed for adults with developmental disabilities. Mike had an intellectual disability and stuttered in all conversation. However, in the art program's story-telling aspect, Mike was given the lead role in a folk tale presented to Senior Citizen's Centers, Nursing Homes and Pre-school Story Hours. In that lead role, Mike never stuttered once! He literally shone.

Mike interacted with his audience and, in those moments, the connection transformed his self-image, his sense of belonging and his opportunity to contribute his unique beauty to a larger community. In the process, Mike also transformed me through the gift of himself.

During 15 years as a Family Support Coordinator, I became aware that listening is a vital component of relationship and spirituality. I think of Barbara, whose daughter has cerebral palsy, an intellectual disability, does not speak or walk, and requires total care. As I listened to Barbara over the years, I was deeply touched by her commitment to caring for her daughter, by her shining tears and her need for respite in order to have time for relationships with the rest of her family.

At the end of a visit, we would part with a smile and a hug. To listen to another is a measure of relationship and acceptance.

Listening to another's soul speaking through their story becomes a deep courtesy of spirit.

Spirituality in the form of hope reminds me of Earl, who was born with a bladder anomaly which was not repaired until he was in his forties. Due to teasing and bullying over his wet overalls, Earl never finished school and worked odd jobs all his life. He lived with his mother in their little home that had wood heat and no running water. With grace and gentleness, Earl cared for his mother as she died of cancer. He hoped to buy a used mobile home and, from his meager income, was saving towards this dream. His hope became a reality when his Home Health community and the Family Support program came together to help fulfill that wish.

I treasure the sheen of a tiny, beaded clown that Earl gave me before he died. It reminds me of hope and of Earl's gracious and gentle spirit in the face of stigma and non-acceptance.

Another Michael, who has quadriplegia as a result of a construction accident, exemplifies the freedom and joy in spirituality. At a high school reunion, Michael was surprised by his classmates' gift of an accessible van. They had recognized the impact of freedom that a van would make in Michael's life. When Michael demonstrated lowering the van lift, rolling his wheelchair into the van and into the driver's position, starting the van and driving, the glow of spirituality was present.

Freedom, belonging, self-image, relationship, the opportunity to contribute and, certainly joy, were all rolled in to an interconnected oneness of giving and receiving spirits!

But most of all, reminding me that one's gifts are more important than abilities is my daughter, Beth. Her spirit significantly opened my heart, transforming my view of the world, ripping it wide. Beth was born with a brain injury and labeled mentally retarded. She saw everyone as a friend and strived to do her best at whatever she tried. One glowing moment, at age 10—in the midst of the constant sensory stimulation that was the Doman-Delacato program for individuals with brain injuries—was her proclamation, "I can do it!" She had tied her own shoestrings for the first time.

Belonging, self-image and freedom shone in her eyes. To see spirit in the most ordinary things, like shoestrings, is sacred to me. Additionally, involving community was deeply soul-filled for me as I worked up to 14 hours a day with Beth's sensory stimulation

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process. The "patterning" aspect of the program required four people, three besides myself, to take Beth through the creeping/crawling motions she had never done as an infant. This "patterning" focused on Beth's eye muscle development to augment her reading ability.

For three years, six friends, neighbors, church members, Jaycees, even strangers who wanted to contribute, appeared at our door twice a day to support Beth's development. The community gifted Beth with acceptance and hope in her ability. Beth gifted them with the opportunity to contribute and a relationship with her unique self.

Then, during Christmas 2007, I experienced the beauty of making and sharing music at Pacesetter's Warren County Center, where adults with developmental disabilities were giving a Christmas program using their new drums and percussion instruments. The drums had been donated in memory of Beth, because drumming was an opportunity to communicate never before experienced. Accompanying the five adult percussionists was another adult, who has a visual disability, singing songs he had heard and memorized through the years, and

a staff person playing the guitar. Of all the songs that day, the most memorable to me was "The Little Drummer Boy". Tears ran down my cheeks as the rhythm and beauty of these souls enthusiastically drummed and sang their place in the world that Christmas. A beautiful "pa rum pa pum pum" indeed!

Ultimately, spirituality is about transformation. It is the transformation of rejection, isolation, labels and fear into acceptance, belonging, relationship, positive self-image, freedom, hope, joy, gifts and the opportunity to contribute. This view of each individual soul journeying through sacred ground can lead to real concern for others, an appreciation of diversity, and a steadily increasing imagination of community and working to clear away obstacles to that inclusion. For me, the heart of spirituality is community, seeing us all as one and always inter-connected. One spirit connects to the grace and beauty in another's spirit and both they and the world are changed in the process.

Joyce Elaine Sievers is chair of the Tennessee Council on Developmental Disabilities.

### **PUTTING FAITH IN GOD'S PLAN**



BY LISA MATTHEISS

"Your baby has spina bifida and hydrocephalus."

The words hung in the air as we tried to digest them. It was July, 1999. Jeff and I had been married almost five years. We were expecting our first baby, a little girl we had already named Emily Christene.

Hundreds of families get similar news every day. At times it comes before the baby is born, as in our case. At other times, the disability is not known until

birth, as in the case of a friend who has a daughter born with Down syndrome. In some cases, the diagnosis is given only after it becomes apparent that the child's development is not on the level of his peers. One friend's young son was diagnosed only recently with Attention Deficit Hyperactivity Disorder (ADHD) and Sensory Integration Disorder.

Whatever the diagnosis and however you get it, you have a choice to make about how you will deal with it, both personally and then as a family. For most families, spirituality, or the lack thereof, plays an important role in how they navigate the fog, especially in the first few

months, and then in the ongoing challenges related to the disability. It wasn't any different for Jeff and me. We came home from the high risk doctor's office on Friday and talked and prayed for quite a while. The following Sunday, we shared the news with our church family and were overwhelmed with their support.

After the diagnosis and before Emily was born, I was reading the ninth chapter of John and came across the description of Jesus' conversation with the disciples. When they were questioning Him about why a man was born blind, Jesus replied, "...that the works of God should be made manifest in him." It seemed obvious, then, that God must have a plan. For weeks, friends, family and church members sent notes, cards and made calls, sharing that same passage of Scripture. We rested in God's plan.

Emily was born on September 11, 1999. Our physical, financial and emotional lives changed forever, but our spiritual lives changed too. It was clearer than ever that we could never do this on our own. Nine years, 16 diagnoses, multiple weeks in the hospital, 14 surgical procedures and the loss of my income all contributed to what could have been chaos. The thread that ran through it all was that verse, "... that the works of God be made manifest in him."

We trusted God more deeply than ever before and depended more on the blessings of family, friends and church. It would take a book to recount all God's blessings in nine years. Our faith increased as we watched miracles happen in Emily's life. As just one example, Emily went through a serious spinal fluid and shunt infection which



Photo by Lisa Mattheiss

Emily Mattheiss and her cousin Courtney

eventually resulted in the decision to remove her shunt. To remove a shunt from a four year old without replacing it was an unprecedented medical procedure for the neurosurgeons. To this day, Emily still has no shunt.

From our knowledge that Emily's life had value because God created her, to the strength we need as caregivers every day, all of our lives have been shaped by the spiritual foundation we possessed personally and as a family before she was born. Praying through medical and educational decisions alone and alongside others, we have watched God's hand continually at work.

We knew from the time of the pregnancy that God had a plan for Emily's life. We did not have to wait long to realize it. Just five years ago, Jeff and I felt God calling us to begin a ministry to other caregivers raising their children who have specific needs. It is something we would never have thought to do before Emily.

As we serve families, it is our goal to provide not only the practical support so important to getting through the crisis, but also the spiritual support as well. We promote prayer and Bible study among families and we encourage mentoring groups that continue to bolster families' service as caregivers. These families continue to support the building of our faith as much as we contribute to theirs.

Our spiritual foundation continues to affect how we establish the same spiritual foundations for Emily and our second daughter, Caroline. We lay that same groundwork when we teach churches and communities to respond to families with special needs. Because God has a plan for the life of each person with and without a disability, there is also a role for each person who comes in contact with those with disabilities during their lifetime. Daily, we are grateful that God has entrusted us with Emily. Her life has provided ample opportunities for spiritual growth as we have watched God work in and through her disabilities at home, church and in our community.

LifeLine Ministry began as a ministry of Hamilton Baptist Church in 2003 and now LifeLine, Inc. is in the process of becoming a a 501(c)3 organization. The Ministry has served over 400 families, primarily in the Chattanooga area, but now has families in nine states. Lisa Mattheiss serves as executive director of the organization, and also on other local, state and national boards and councils.















### PARTNERS IN POLICYMAKING™ CLASS OF 2008-09 GETS UNDERWAY

"I believe I must learn all that I can to squash the fears and create the best possible future for my son....maybe I can modify the world and make it a more accepting place for him. Gotta try."

"I want the wisdom and knowledge to empower more people in my city, state and nation. I also would like to help people with or without disabilities to know that one person can make a positive difference in this world."

"As I have worked with several families and had been part of a family with a person with a disability, I understand the tremendous impact legislation has upon peoples' lives. I want to become a better advocate to ensure that my brother and other families like ours receive the services, support and assistance which they not only need, but also are entitled to."

#### BY NED ANDREW SOLOMON

This past May, Partners
Director, Ned Andrew Solomon,

Council on Developmental Disabilities Executive Director, Wanda Willis, and governor appointed members of the Council reviewed the stack of submitted Partners applications in the hopes of selecting the class that would attend the seven September '08 through April '09 sessions.

That task is never easy. The panel ventured to create a diverse group that would take their extensive training and become leaders in their communities, as advocates for themselves, for their loved ones and for others who have not yet had the opportunity to attend Partners.

As of the printing of this magazine, the current class will have the first three sessions under their belts. During those trainings, the Partners learned about the history of the disability experience, People First Language, building inclusive communities, best practices in inclusive education, self-determination and supported living, along with overviews of the waiver system and the State budget. They will look forward to much more information and numerous networking opportunities in the remaining four sessions.



The Council is very proud to present the Partners 08-09 Class:

Stevie Bailey, Nashville

Deborah Balthrop, La Vergne

Meghan Burke, Nashville

Tina Cicirello, Nashville

Dennis Clark, Oliver Springs

Jacqueline Dowlen, Nashville

Josh Gibson, Nashville

**Sheryle Guinn**, *Lafayette* 

**Shirlene Harbert**, Antioch

Bryan Hilbert, Knoxville

Cheri Howlett, Powell

Thomas Jerdon, Collierville

Allison Kemp-Eoff, Murfreesboro

Brandi Mareno, Tullahoma

Cynthia Martin, Tullahoma

Michael Mevis, Kingston Springs

Mark Montgomery, Hermitage

Michele Priddy, Hendersonville

Debbie Riffle, Humboldt

Connie Robinson, Germantown

Anthony Sledge, Memphis

Marilyn Sortor, Memphis

Tommi Stephenson, Nashville

Tammie Taylor, Memphis

Josh Turner, Nashville

Jo VerMulm, Murfreesboro

Nichole Wilkins, Memphis

## UNCLE JOE LOVES TO PRAY

BY JANE SMITH

"You can lead a horse to water, but you can't make it stand on its head." That is the

favorite (mis)quote of my Uncle Joe, who was born February 7, 1946, in Knoxville to J.B. Rainwater, retired soldier, and Chattie Stokely Rainwater, a teacher. Joseph Stokely Rainwater was born with Down syndrome.

The old doctor who assisted Joe being born told them to "put it away where it will get the care it needs." These parents had never heard of such a thing as "putting away" a newborn, sweet-faced baby, so they took little Joey home and loved him.

Joe's mother, after seeing that he could learn, helped him become the devoted Christian he is. She read the Bible to him nightly and taught him to pray.

The Lord said, "Make a joyful noise." He did not say you had to carry a tune. My Uncle Joe loves to sing and sings a song at every Sunday evening service. He may not "carry a tune", but many have said he sings from his heart and that his songs are uplifting to them. He also thinks no one else can sing but him, and gives people near him "the look" if he thinks they are off key.

Joe's most important gift is prayer. He prays for everyone he meets. People call our house frequently to ask for Joe's prayers. Once, when a dear friend was dying of cancer, she had someone call us and ask us to bring Joe to see her. She asked him to pray for her and later reported that she felt better after that than she had in weeks. She died a few days later, but we knew that Uncle Joe's prayer had helped her cope with her illness and helped make death a little easier to face.

We believe Joe's heart and mind are uncluttered by the daily stresses we all have and, therefore, he has a better chance of "getting through" to God. Joe also prays expecting results because he simply believes he is talking with God and God listens and answers prayer. We all should take a lesson from Uncle Joe here!



Jane Smith (left) and Joe Rainwater

#### **UNCLE JOE'S PRAYERS**

Every day he prays, But Saturday is special to him. The week is done and the pressures of Work are over...for a while. It is the time for the real work Of his life to be performed. Two hours in the morning And two in the afternoon. Though time is irrelevant Uncle Joe can't tell time. He just prays until needs are expressed And his soul is filled. And oh! How his soul is filled! Because you see, he prays With perfect confidence (some say the faith of a child) That God listens and answers his prayers.

He prays for his family
Because he loves them enough
To care for their lives
Even when they do not.
When others are unkind or short-tempered
With his slowness
He prays for them to be blessed with patience.
He prays for the church;
That there will be a great revival
And the people will turn back to God
And live in harmony.

He promises everyone he meets
I'll pray for you. And he does,
Every day, with a double dose on Saturday.
So be aware, when you meet Uncle Joe
Your life is going to change.
And when things start looking brighter
Remember, it is someone praying for you.
And that someone, due to faith
Has a direct line to God.

## INCLUDING PEOPLE WITH DISABILITIES IN FAITH COMMUNITIES

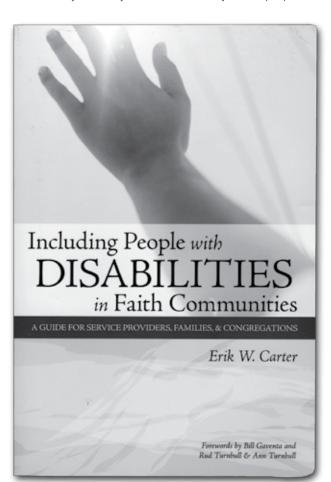
#### BY ERIK W. CARTER

REVIEW BY MEGAN GRIFFIN

As an Assistant Professor of Special Education,

Dr. Erik Carter has produced much research and writing on the inclusion of students with special needs within both classrooms and school systems as a whole. Maintaining his focus on inclusion, this book explores the ways that people with disabilities can more fully participate in their faith communities.

Noting the progress toward fuller inclusion in the American public school system and in the workplace, Dr. Carter calls for similar efforts in faith communities across the United States. These efforts might best begin with individual faith communities taking an honest look at the ways that they exclude or effectively include people



with disabilities in the practices of their faith. Dr. Carter provides an excellent community needs-assessment that identifies "indicators of welcome" within faith communities, as well as physical and attitudinal barriers to people with disabilities.

Having provided this assessment for communities to identify areas of strength and weakness in their inclusive practices, Dr. Carter goes on to explain ways that both religious and lay leaders can create and foster more inclusion in their faith communities. First, he addresses how communities can welcome people with disabilities and their families into the congregation. He also applies this ethic of welcome to those who are already a part of the community, but whose participation is limited by a variety of barriers. Finally, he considers ways that faith communities can actively help people with disabilities by connecting them to community supports over "the other six days" that they are not participating formally in the community's faith services.

One concrete example of a way that faith communities can welcome people with disabilities is to fully include them in religious education programs. Dr. Carter takes the principle of individualized planning—as it is used in both schooling and transition for many people with disabilities—and applies it to religious education. This principle focuses on the different needs an individual has and tries to match supports to those needs. His value of inclusion also emphasizes that these needs should be fulfilled among an individual's peers—not in a separate program or classroom—as much as possible.

This template for developing more fully inclusive religious education is just one example of the issues covered in Dr. Carter's book. The plans and ideas he provides, along with the many resources listed throughout the book, will prove invaluable to both people with disabilities and their families, as well as religious and lay leaders. Regardless of a faith community's current level of inclusive practices, Dr. Carter's book is a great starting point to those who seek the full participation of people with disabilities in their own congregations.

Megan Griffin is a second-year doctoral student in Special Education at Vanderbilt University. One of her interests is the accessibility of spiritual and religious communities to people with disabilities and their families.



Photo by Rob Taylor

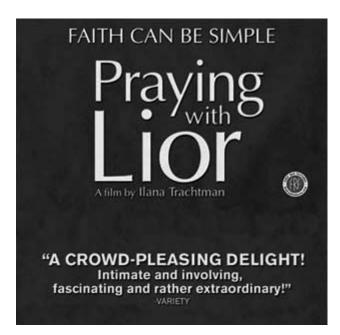
### PRAYING WITH LIOR EDUCATES, ENTERTAINS AND ENLIGHTENS

BY COURTNEY TAYLOR

"We have a grandchild who has Down syndrome," the child's

grandmother shared after a screening of the documentary film, Praying with Lior, at Vanderbilt University. "She is not as high functioning as Lior, but she too has a sense of belonging within a community where she finds comfort and can express joy. It was wonderful to see the importance of community so sensitively uplifted in the film. I'm really glad we saw it."

The documentary film, *Praying with Lior*, reminds us of how integral a sense of belonging within a community is for an individual's well-



being. We all need to experience a sense of belonging and a place where we can safely express joy and pain, a place where we can share our gifts and talents and also receive another's, providing a mutual experience for all involved. This is the practice of full inclusion. The experience of being fully included, can, at its best, strengthen a sense of personal power and foster connections with that which is beyond the self. This certainly is the case for Lior Liebling.

Lior is a 12-year-old, typical teenage boy who also happens to have an intellectual disability. *Praying with Lior* documents the year leading up to his Bar Mitzvah. It allows viewers both hilarious and emotional glimpses inside the joys and challenges of a family, a classroom and a faith community that have a young and gutsy member with an intellectual disability.

"I was not looking for a film subject, and I wasn't particularly interested in disability," said Ilana Trachtman, the film's producer and director. "I'm not sure I ever *thought* about disability. What I was doing had no connection to my career as a producer/director of TV documentaries. I was actually trying to pray."

On a retreat with a new spiritual community during the Jewish New Year and Yom Kippur, Ms. Trachtman sought to reclaim a lost sense of connection to her prayers. As she sat trying to remain present and focused on the act, she heard the prayers of Lior.

"I heard Lior's unabashed, off-key, ecstatic voice," remembered Ms. Trachtman. "When I turned to look at the source of this sound, I was struck to see a boy with Down syndrome. And I was surprised to find myself envious of this child, who could pray as I wished I could. Over the course of this retreat, I stalked Lior, looking for the secret to his

prayer. When I heard he was having a Bar Mitzvah, I pictured the movie version. And then I realized that I could make it."

When she approached Lior's family with the idea, they told her they had always wanted someone to make a documentary film about Lior's Bar Mitzvah. So, the filming commenced. The moments in Lior's life and in the lives of those who surround him that Ms. Trachtman documents are honest and real. The film explores inclusion, the myriad issues that typically developing siblings face, futures planning, and even death and grief. It not only is a portrait of a strong and loveable individual and his family and community, but it also is a tool for educating its viewers and is the "centerpiece of an ambitious outreach campaign."

"This isn't a film just about a kid named Lior," said Ms. Trachtman." If it is just a film about Lior, I have failed as a filmmaker. I mean for this film to change the way people with disabilities are perceived and received by faith communities. And not only that. I mean for this film—and the outreach work it has led us to do—to encourage us, as a society, to look at how completely and equally we value and include each individual."

*Praying with Lior* is a tool that any community, regardless of its religious or nonreligious affiliation, can use to educate people on issues of inclusion. It is a delightfully entertaining work of art and life, and the

insights it inspires will leave viewers touched, enlightened and changed.

To reserve a DVD of *Praying with Lior* for your library, faith-based organization, school or other not-for-profit educational institution, visit www.prayingwithlior.com/dvd.html.

Courtney Taylor is associate director of Communications and Dissemination at Vanderbilt Kennedy Center



Still photo from Praying with Lior

## DISABILITY AND SPIRITUALITY IN THE LIFE OF LORA ANNE SPENCER

BY CARLENE I. LEAPER



Lora Anne Spencer, Memphis, TN

While spirituality has been increasingly recognized as potentially significant in the lives of people with disabilities, it is also recognized as an under-explored area in scientific research. Virtually absent from the literature are the voices of women with disabilities concerning the role of spirituality in their lives.

I want you to meet Lora Spencer. She is a person with a physical disability and, when I first met her, her faith was evident. One of the central findings from our talk was that spirituality and disability were intricately related. Lora consistently described disability and spirituality as core dimensions of her life that were emergent, interactive and interdependent.

#### IN LORA'S OWN WORDS:

"Attending church motivates me. My spirit is lifted while singing and listening to the pastor. I have a background of spiritual praise dancing which is my way of showing God appreciation of His work. The gift of giving motivates me also. I give donations to the United Way Foundation and have participated in the Jerry Lewis Telethon.

"My faith in God is a strength. Having the strength to turn bad situations into positive keeps me going every day. I am building strength to walk with the help of my PA [personal assistant]. I take more steps each day. I am determined to walk on my own. I can do all things through Christ, who strengthens me. I am able to go to work and help others in the office. I have an easy task in the office, for example, shredding paper. My personality is strength. Even though I have a disability, smiling and greeting customers on a daily basis symbolizes my great spirit.

"Don't let the devil steal your joy. Lift God up!"

Carlene I. Leaper is executive director of The Arc of the Mid-South

## DISABILITIES, RELIGION AND SPIRITUALITY RESOURCES

#### COMPILED BY COURTNEY TAYLOR

Religion and spirituality can play powerful

roles in the lives of practitioners and in how a culture—its habits and customs—are shaped. For many people, participation in a faith community offers comfort, support and an opportunity to grow in compassion, forgiveness and generosity. The list of religious and spiritual disability-related resources below is selective. It contains national interfaith Web resources that may be helpful for families, professionals and faith communities as they work toward full participation of individuals with disabilities.

**Tennessee Disability Pathfinder's** database contains a number of interfaith organizations and spiritual/religious resources located in Tennessee. To view those listings, visit: http://kc.vanderbilt.edu/tnpathfinder. Click on the icon "Interfaith Resources".

#### **ECUMENICAL AND INTERFAITH WEB RESOURCES**

The American Association of People with Disabilities houses the Interfaith Initiative, a program dedicated to supporting people with disabilities and their families as they seek spiritual and religious access. The Initiative works to bring the powerful and prophetic voice of the faith community to the 21st century disability agenda. Directed by Ginny Thornburgh, this program was formerly a division of the National Organization on Disability.

http://aapddc.org/AAPDRedesign/Interfaith/Interfaith.html

The American Association on Intellectual and Developmental Disabilities houses the Religion & Spirituality Division, an interfaith, interdisciplinary association of professional, ordained and lay people who "journey" with persons with developmental disabilities and their families. www.aaiddreligion.org/about

The mission of the Web site, **Beliefnet**, is to help people find and walk a spiritual path that will bring comfort, hope, clarity, strength and happiness. The site provides inspiring devotional tools, access to noted spiritual teachers and clergy worldwide, thought-provoking commentary and a supportive community. The site is not affiliated with any spiritual organization or movement. A search on "disability" provides a range of discussions, articles, blogs and videos. www.beliefnet.com/Search/Site.aspx?q=Disability

The **Center for Spirituality, Health and Disability** concerns itself with the relationship between spirituality, health and healing, the significance of the spiritual dimension for contemporary health care practices and the theology of disability. Located at the University of Aberdeen, the Center is a wonderful resource on a variety of spirituality, health and disability-related topics to enable academics,

researchers, practitioners and educators to work together to develop innovative and creative research projects and teaching initiatives. www.abdn.ac.uk/cshad/

The **Congregational Resource Guide Online** lists academic resources and articles that focus on barriers to participation, building issues and congregational vitality (welcoming persons with disabilities into the congregation).

www.congregationalresources.org/ShowCat.asp?TC=185

**Coping.org** offers the "Tools for Coping Series", which includes online manuals and resources for coping with a variety of life's stressors. "Addressing the Spirituality Needs of Children with Disabilities and their Parents" is an article that helps parents address the spiritual needs of their children with disabilities and includes a long list of print resources. www.coping.org/specialneeds/spirituality.htm

"Disability in the Context of Religion, Spirituality, Belief and Morality, in Middle Eastern, South Asian and East Asian Histories and Cultures: An Annotated Bibliography" lists and annotates modern and historical materials in translation, sometimes with commentary, relevant to disability, mental illness and deafness in the context of religious belief and practice in the Middle East, South Asia and East Asia.

www.independent living.org/docs7/miles 200707.html

**Disability Resources** is a nonprofit organization established to promote and improve awareness, availability and accessibility of information that can help people with disabilities live, learn, love, work and play independently. The site provides links to Web sites that offer information designed to encourage and support the accessibility of religious organizations and facilities. www.disabilityresources.org/RELIGION.html

The **Elizabeth M. Boggs Center on Developmental Disabilities** iin New Jersey has developed a project on Faith-Based Supports. The Center sponsors a variety of activities and projects that encourage congregations to include and support people with disabilities and their families. A "products" page lists a number of resources on religious and spiritual topics as they pertain to individuals with disabilities. http://rwjms2.umdnj.edu/boggscenter/projects/Faith\_Based\_Supports.htm

**Faithability.org** provides links and resources for people of many faiths who are interested in the intersection between religion and the disability community. Resources are varied, including first-hand perspectives, educational supports and theological works. www.faithability.org/

Family Village is a Web site for children and adults with disabilities, their families, and their friends and allies. Family Village brings together thousands of online resources in an organized, easy-to-use directory. The Family Village Worship Center includes religious/faith/spiritual resources for those who have disabilities. www.familyvillage.wisc.edu/Worship.htm

The **Journal of Religion, Disability & Health** provides an interfaith, interdisciplinary forum that supports people with disabilities and their families through religious, spiritual, clinical, educational and scientific perspectives. There is a growing awareness of the importance of spirituality and religion in health and human services. This journal addresses the critical ethical, moral and spiritual issues raised by people with disabilities

in health and rehabilitation services. www.haworthpress.com/store/product.asp?sid=WFKSCF63G C2D8JUF5JEW3288J3SX0GG9&sku=J095

The mission of the **National Center on Physical Activity and Disability (NCPAD)** is to promote the health benefits that can be gained from participating in regular physical activity. Yoga, for many, not only provides physical benefits, but also provides a vehicle for spiritual practice. NCPAD offers advice and examples of how to adapt common yoga practice for persons with disabilities. www.ncpad.org/disability/fact\_sheet.php?sheet=345

Courtney Taylor is associate director of Communications and Dissemination at Vanderbilt Kennedy Center



## THE IMPORTANCE OF BEING INCLUDED IN A FAITH COMMUNITY

BY MARK E. MONTGOMERY

My first experience with inclusion in a faith community

happened when I was four years old. It was the early 1970's, and it was rather difficult to approach some Catholic priests. On Palm Sunday, during the reading of the Passion, I became very upset. I guess it was when I really started to pay attention to what was going on in church every Sunday. After Mass I was very agitated and it took some time for my mom to get the reason out of me—which was that I was disturbed after learning about the crucifixion. Having a visual problem I didn't understand what was happening.

My mom spoke to one of my nursery school teachers about it and they arranged for me to meet with a priest who took the time to show me the altar. He explained to me what happens on Palm Sunday. I give my mom a great deal of credit for understanding what had happened, and for seeking out a priest who would talk to me and explain to a four year old with a vision problem what exactly happens on Palm Sunday. I think that for this time period it was very unique and is a wonderful example of inclusion.

My next experiences happened much later. After high school, I began to sing in my church's folk group. I couldn't read music, but with the help of my folk group leader I learned the words of

the songs and was able to contribute in a small way to the Mass. As the years went on I even was asked to sing at weddings and several funerals. I have played the guitar since the fifth grade. Again, I couldn't read music to save my life but learned how to play by ear. I have played from time to time with my folk group. It is such a rewarding experience to be able to share one's gifts with others.

Also, I became a lector at my parish back home. I would Braille the readings out the week before and practice reading aloud. One of the last opportunities I had to lector at my old parish was, ironically enough, Palm Sunday and the reading of the Passion.

I have served on a parish council as president. I think growing up in a small town and attending Mass or services with people you know and have grown up with is important to being included in a faith community. There is a sense of belonging that you get from a small town. I have moved away now to a larger town/city. I have to establish those connections again with people. It is harder now to make those connections, but I am trying. It is an important part of who I am.

Mark E. Montgomery, J.D., is executive director of the Statewide Independent Living Council of Tennessee

# INCLUSION OUTREACH EFFORTS ENTER COMMUNITIES OF FAITH

BY COURTNEY TAYLOR

Architectural, attitudinal, communication, programmatic

and liturgical barriers have played a large role in how easy or difficult it is for an individual with a disability to be fully included in a community of faith. Self-advocates, the disability service world and disability-related legislation have addressed and have made great strides in the areas of education and the workplace, yet full inclusion in the church, the synagogue, the temple and on the Sangha has received less attention.

"When a child is diagnosed with a disability, the first place a family turns is to their doctor," said a participant in a focus group on disability, religion and spirituality held at the Vanderbilt Kennedy Center (VKC) last year. "The second place many people turn is to their spiritual community. Pastors, rabbis and leaders of all the world's religions in all of our faith communities need to be able to support families across the life span and stages. Congregations need to have knowledge and to be able to give good advice to families, on both spiritual and practical issues related to disabilities. Families need to feel their needs are important and that they are included."

Full inclusion of individuals with disabilities in religious and spiritual communities means opportunities for full participation in all activities within the life of the congregation. It means an opportunity to share one's gifts and talents, and a chance to contribute to the community in ways that strengthen both the community and the individual. It means an individual's and a family's well-being is nurtured and supported within the community. It is a reciprocal relationship that ministers with rather than to.

A series of focus groups at the VKC were held to assess the need for and the areas where technical assistance from the VKC might be useful to religious and spiritual communities.

Focus group participants included religious and lay leaders, individuals with disabilities and their families, disability service providers, and interested Vanderbilt Divinity School and other Vanderbilt University faculty and students. Participants assured VKC faculty and staff that indeed there is a great need for assistance and an even greater need to bring these issues to the forefront.

"Ideally, I think communities want to include everyone," said a local minister and focus group participant. "We want to help but don't

know what to do next. I think a lot of congregations feel too little, too isolated or too poor to do anything. People want to do the right thing but don't know how."

After the focus groups, a Disability, Religion and Spirituality committee was formed at the VKC. Thanks to receiving a modest grant from the Vanderbilt Center for Medicine, Health and Society, several activities are underway to aid congregations and individuals with disabilities and their families in achieving inclusive communities of faith.

A primary activity is the development of an interfaith survey for religious leaders, individuals with disabilities and their families and congregation members, administration of which began across Tennessee in November, 2008. The survey will assess how easy or difficult it is to include individuals with disabilities in congregations and how well individuals and families think their communities are doing.

A second activity is a public lecture to be given at the VKC on February 5, 2009, by Reverend William Gaventa, director of community and congregational supports and an associate professor of pediatrics at the Elizabeth M. Boggs Center on Developmental Disabilities, Robert Wood Johnson Medical School. Rev. Gaventa's talk is entitled, "Where Personal, Professional and Communal Ethics Meet: The Challenge and Promise of Inclusive Spiritual Supports with People with Developmental Disabilities and Their Families."

Yet another activity is making connections with future religious leaders. A presentation will be given at the Association for Theological Field Educators on the topic and promise of disability-related internships for seminary and divinity school students. The VKC is hosting its first student intern/trainee from Vanderbilt Divinity School, Sue Francis, who is raising awareness on issues of accessibility and inclusion through assistance with all of the aforementioned activities, as well as focusing her thesis on inclusion within the Christian perspective.

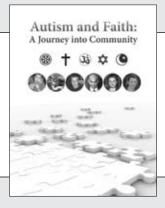
Of course, this is only a start. While many congregations are doing well in their efforts toward full inclusion, assistance in many areas is still necessary. As people increasingly become aware of the importance of inclusion in communities of faith, more doors will be wide enough, more accommodations will appear in rituals, and

more individuals and families with disabilities will know that their presence is a necessary component for the well-being of the community.

While the attention thus far has been on faith communities, the point made by one focus group participant must not be overlooked: "Our conversation continues to go to faith communities, but spirituality is really a broader concept in all walks of life. When we think about spirituality, it is really helping us think about the worth and purpose of life. I hope that eventually it can be broader than just congregations. People want to have worth and value in the community.

"We need to find ways to understand that these outreach efforts should really be a broader issue. The faith community cannot do this alone. My father was a pastor, but he was one person. He always talked about priests without robes. We need to look at this work as an interdisciplinary way of impacting the broader well-being of the community."

Courtney Taylor is associate director of Communications and Dissemination at Vanderbilt Kennedy Center



# Autism and Faith: A Journey into Community

The New Jersey University Center of Excellence in Developmental Disabilities (UCEDD), The Elizabeth M. Boggs Center, has developed a new resource entitled *Autism and Faith: A Journey into Community*. The guide provides an introductory, empowering resource for use by clergy, religious educators and families to develop inclusive spiritual supports for children and adults with autism and their families and recognize the unique gifts that congregations and people with autism can offer to one another.

The fifty-two page guide for including individuals with autism in faith communities was developed by the Autism and Faith Task Force of The Boggs Center and the New Jersey Center for Outreach and Services for the Autism Community (COSAC). The Task Force worked for more than two years collecting stories and experiences from families, best practices and strategies from clergy and human service professionals, and resources from around the country. The guide features more than 15 short articles written by clergy, parents, professional experts on autism, religious educators and people with autism, illustrated by numerous sidebar stories and examples from families who shared their experiences, both positive and negative, with their own faith communities in New Jersey. It is interfaith, including examples from Christian, Jewish, Hindu and Muslim communities.

Sample articles include:

- Autism Life Cycles and Faith Communities
- Autism and the Family
- Creating Sanctuary: A Clergy's Guide

Linda Fiddle, the executive director of The Daniel Jordan Fiddle Foundation, which provided the funding for the printing of this booklet, notes, "This new resource will create a better understanding by faith communities of autism and the challenges and joys families and individuals find as they seek to participate. It also is our hope that those with autism will use this as a vehicle to open the doors to their faith communities as a means of support and spiritual growth that The Daniel Jordan Fiddle Foundation believes is an important component to lifetime wellness."

For more information, please contact Rev. Bill Gaventa, director of Community and Congregational Supports at The Boggs Center, 732-235-9304 or e-mail bill.gaventa@umdnj.edu.

To place an order for the \$5.00 guide, please visit The Boggs Center Web site at http://rwjms.umdnj.edu/boggscenter or call 732-235-9317.

Reprinted with permission from the November, 2008, A D D  $\,$  U P D A T E.

BY WHITNEY GRIFFIN, LMSW

## PATHFINDER NEWS AND RESOURCES ON DISABILITY AND SPIRITUALITY

For a person with a disability and family members, access to a full life of faith may be just as important as access to education, employment, health care or other life areas. People with disabilities have gifts and talents to bring to their congregations.

In addition to the resources listed here, contact your church or denomination for information. National and international offices of world faiths and denominations provide information on accessibility and worship and education resources. You can contact your clergyperson or search the Internet for information on your faith or denomination.

#### **TENNESSEE INTERFAITH RESOURCES**

Christian Church Foundation for the Handicapped (CCFH) provides materials designed to help faith groups include people with a variety of abilities. http://www.ccfh.org/

The Junior League Family Resource Center's **Faith Community Support** offers a variety of ideas, agencies and other resources to improve care for children with disabilities or special health care needs and their families within any faith community. http://www.vanderbiltchildrens.com/interior. php?mid=996&mode=&TopicID=46&search\_topics=&GenCatID=&show=topic

Joni and Friends is a Christian ministry geared toward disability outreach with an area ministry in Knoxville. Joni and Friends programs include an annual Family Retreat and Wheels for the World ministry. Their 'Fellowship of Friends' meets regularly to encourage disability ministry at the local church level.

http://www.joniandfriends.org/

**Just As I Am** is an organization dedicated to serving children, youth and adults with disabilities and their families through education, therapy,

research and supportive services. http://justasiamfoundation.org/

**Stone Soup** is a part of the Redeemer Fellowship family in partnership with Judson Baptist Church in Nashville. Stone Soup offers many programs intended for families of children with all abilities to fellowship together around a high quality, learning focused approach to life. http://www.stonesoupnews.com/

**Library Services for the Deaf and Hard of Hearing** offers information on inclusive
ministries statewide.
www.tndeaflibrary.nashville.gov

#### **OTHER PATHFINDER NEWS**

Pathfinder is continuously trying to provide the most accurate information. If your agency needs to update their information, please contact Tracy Pendergrass at tracy.pendergrass@vanderbilt.edu.

Missing out on the latest events? Check out Tennessee Disability Pathfinder for all disability related events across Tennessee. If you would like to add your event, please contact Tracy Pendergrass at tracy.pendergrass@vanderbilt.edu.

The Pathfinder Hispanic Outreach team will make several trips to multiple counties in East Tennessee to network with staff and Family Support providers, and identify bilingual providers and families needing services. Included will be a meeting with a conference planning committee in Knoxville to coordinate the launching of Camino Seguro East. Claudia Avila-Lopez is the contact for Hispanic Outreach and can be reached at claudia.avila-lopez@vanderbilt.edu.

Whitney Griffin is information and referral services coordinator with Tennessee Disability Pathfinder

#### FOR FURTHER INFORMATION

### Tennessee Disability Pathfinder

English & Español (615) 322–8529 (800) 640–4636

TTY/TDD users: please dial 711 for free relay service

#### www.familypathfinder.org

tnpathfinder@vanderbilt.edu



Tennessee Disability Pathfinder has phone, Web and print resources in English and Spanish to connect the Tennessee disability community with service providers. Referral services, free of cost, are provided to persons with disabilities, family members, service providers and advocates. Pathfinder is a joint project of the TENNESSEE COUNCIL ON DEVELOPMENTAL DISABILITIES and the VANDERBILT KENNEDY CENTER FOR RESEARCH ON HUMAN DEVELOPMENT.

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VISIT WWW.TNDISABILITYMEGACONFERENCE.ORG

PHONE: 615-248-5878 • TOLL FREE: 1-800-835-7077



### \*\* TENNESSEE SPOTLIGHT



The Mayor's Advisory Committee for People with Disabilities and the Vanderbilt Kennedy Center for Excellence in **Developmental Disabilities** hosted their annual awards ceremony and reception October 23 at the Metro Government Office. In keeping with this special issue of Breaking Ground, we highlight the Communications Award, given to Pat Pickett, who works with the residents of Clover Bottom Developmental Center as the pastoral care provider. Rev. Pickett was recognized as connecting the residents "with themselves, the community and the greater good through the use of art and spirituality." [See Breaking Ground, Arts Issue, October 2008, pages 16-17, for an article about Rev. Pickett.] Creative Expressions XIV artists were honored and other award recipients were:

Mack West Children's Award

#### **Claire Puryear**

Trey Pointer Young Citizen Award

#### Whitney Qualls

Jo Andrews Award

**Dena Gassner** 

Volunteer

Sarah Jane Mitchell & Q-bert

Professional

Lori Kissinger & Carole Moore-Slater

Organization

**Frist Center for the Visual Arts** 

Legislator

**Janis Sontany** 

Health Care Provider

Ralf Habermann, MD & Beth Malow, MD

Family

Janet & John Shouse

**Employer** 

Cryosurgery

Educator

Jim Oldham & Christian Sawyer

Arts

**Melissa Brett** 

On Saturday, September 13, over 2,000 Tennesseans came together at Nashville Superspeedway for Walk Now for Autism, Autism Speaks' fundraising and awareness event. Over \$200,000 was raised for autism research, family services, awareness and advocacy. Allison Nahmias, a research assistant for TRIAD and a member of the Vanderbilt Kennedy Center team, was the top walking fundraiser in Tennessee, raising over \$4,000.

Special Education Director, Michael Remus, of the Deer Valley Unified School District (DVUSD) in Phoenix, Arizona, was presented with the

2008 TASH/Wal-Mart Breakthroughs in Inclusive Education **Administrator of the Year Award** at the annual TASH meeting on December 5 in Nashville. Mr. Remus is the former director of special education for the Williamson County School System and a former executive director of The Arc of Tennessee.

The purpose of this award is to honor important and courageous contributions of individuals in advancing inclusionary practices and equitable opportunities for students pre-school through 12th grade, particularly those with the most significant disabilities and support needs. TASH recognizes local school systems and the professionals who are leading the way in guiding students with disabilities toward academic and social success. For the second year TASH has partnered with Wal-Mart to present the Breakthroughs in Inclusive Education Awards program.

Partners 04-05 graduate Jawanda Mast was chosen for this year's Chiquita Morris Award. A parent of a child with a disability and an advocate for inclusive school practices for all children, Ms. Mast collaborated with her local school system in Memphis to provide inclusive schooling practices for her child and other children.

**Canine Companions for Independence** recently retired assistance dog Cary, a Labrador Retriever partnered with Sara Elizabeth "Lizzy" Solomon of Nashville, was honored at the 2008 American Kennel Club Awards for Canine Excellence in the Service Category. With Cary's help, Ms. Solomon has become a role model in her community and helped many others with disabilities. Together they serve on a panel for disability awareness training and have worked with employees and volunteers at community organizations, including the Frist Center for the Visual Arts and the Country Music Hall of Fame in Nashville, as well as the Creative Discovery Museum in Chattanooga.

Youth Leadership Forum (YLF) 2005 graduate Will Ferrell was certified as a Microsoft Certified Systems Engineer in July. He currently is working on the **Apple Care Technician Training**.

Partners 03-04 graduate **Gina Lynette** is a Financial Advisor with Capital Financial Services in Brentwood. As part of Capital's **SpecialCare Team**, her focus is providing families and individuals with disabilities the tools they need to build a strong financial home, plan for retirement, and provide for their loved one while protecting their access to government benefits.

East Tennessee Technology Access Center's Learning about Freedom music and story-telling will return to area libraries in 2008 and 2009, thanks in part to Arts Build Communities grant funding from the Tennessee Arts Commission and the Culture Alliance of Knoxville. These classes are designed to help children and adults with and without disabilities learn more about how the



Civil Rights movement influenced the Disability Rights movement and resulted in many of the rights and privileges we all enjoy as Americans. The 2008-2009 series will include two nationally recognized artists, musician **Sean McCullough** and musician/storyteller **Georgi Schmitt**.

In early October, a **Career Day**, sponsored by the **Upper Cumberland Human Resource Agency, Training Resources Employment Network for Disability Services (TRENDS)**, and the **Cookeville Noon Rotary Club**, brought together over 100 students,
26 teachers and teaching assistants and more than 60 visitors from
the community to visit with 55 representatives from agencies and
companies that are passionate about employment opportunities for
youth and adults with disabilities. The annual event is coordinated by **Danielle Cason**, a Disability Program Navigator.

During the **2008 Memphis Buddy Walk**, Partners 02-03 graduate **Keith Greenwald** was the second place fund raiser, gathering nearly \$3700 in donations. As a way of showing thanks for his efforts, Mr. Greenwald was awarded two airline tickets to fly anywhere in the United States. In addition, he was honored by **Paul Landers**, one of his support staff from **West Tennessee Family Solutions**, at their retreat in early September.

Partners 05-06 graduate **Suzette Byrd** was one of the winners of the **2008 Tennessee Justice Center Mothers of the Year** awards. Annually, the TJC honors mothers who have devoted their time and energy to advocating for their loved ones, as well as others in the community.

**Carrie Dean**, a graduate of the 2008 Tennessee Youth Leadership Forum, was accepted into her high school's **National Honor Society** in Paris, Tennessee. Ms. Dean also was elected vice president of her school's speech team.

Partners 07-08 graduate **Corinne Derenburger** is now a certified Life Coach and a Life Purpose and Career Coach. In addition, **Ryan's Hope**, the non-profit organization Ms. Derenburger founded, was awarded the **2008 Innovator Award** from the **United Way of the Mid-South** for its support of children with disabilities.

Partners 00-01 graduate **Kathy McGee** and her family just returned from her son, **Jonathan**'s, dream trip. For more than two years, Mr. McGee planned and saved to go to Austria and Germany. The trip would only take place if he had fully recovered from three hip surgeries and was able to walk independently—which he did, and could. The family took Eurail trains, buses, horse-drawn carriages and boats all over Germany, touring castles, churches and museums. Additionally, here in the States, Mr. McGee has earned all of his Scout badges and is beginning his Eagle Scout project.

H. Carl Haywood, PhD, professor of psychology, emeritus, professor of neurology, and a member of the Vanderbilt Kennedy Center, has been appointed to serve as a member of the Committee on the Impact of Mobility and Change in the Lives of Young Children, Schools, and Neighborhoods. The committee is under the Board on Children, Youth, and Families, a shared activity of the National Research Council and the Institute of Medicine.



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